

# ADD UPDATE

*The American Dream Belongs to Everyone*

MAY 2008



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## Message from the Commissioner

The quality of an individual's life can often be measured by the quality of the care he receives.

For people with developmental disabilities, obtaining the right net of services and supports can be the key to living a fulfilling, independent life. Part of ADD's mission is to promote independence by ensuring that individuals with developmental disabilities have access to services and supports that allow them to lead full lives as part of a community.

Individuals with developmental disabilities need clear and consistent information regarding services and supports, as well as access to tools to enable them to make informed decisions, choose between service providers, and manage various services.

Direct care services can allow an individual a level of independence that would not otherwise be possible. Direct care workers provide one-on-one support, assisting individuals with daily tasks, helping them get to appointments, and allowing them the autonomy to achieve their goals. Quality care provided by skilled, car-

ing professionals can alter the course of an individual's life.

Nationwide, we face a disturbing shortage of well-trained direct-care workers — home health aides, certified nursing assistants, and personal care attendants. Obtaining vouchers for direct care can be challenging, to say the least.

This issue of the ADD Update addresses programs that are working to solve the problems associated with access to direct care, and to also improve the quality of the services available. This issue also looks at grantee programs that are building innovative solutions to the need for a variety of services and supports.

In addition, new technology is changing the way services are provided. With the evolution of high-tech solutions to everyday problems, new doors are opening, and new opportunities are becoming available.

The following pages provide insight into just a few of the ways that direct care impacts the lives of individuals with developmental disabilities and their families.

## Tennessee Collaborates on Legislation



In 2000 the Tennessee legislature recognized the need for services for children and adults with developmental disabilities other than cognitive disabilities. A provision was included in its revision of Title 33 of TN Code.

However, since the law was changed, no funding has been allocated for these persons, programs have not been expanded to include these persons, and comparable programs have not been developed to enable persons to receive services they need in their homes and communities.

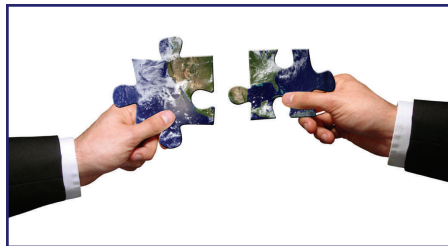
To address this issue, legislation was introduced and passed in 2006 that created a Task Force charged with studying the needs and developing a cost effective plan to provide services. This diverse Governor-appointed Task Force included three TN DD Network Partners: the *Council on Developmental Disabilities, Disability Law & Advocacy Center, and Vanderbilt University's Kennedy Center UCEDD*.

After a year of research, discussion, and planning, the following recommendations were made:

- The State of TN should provide an array of home and community-

based services to persons with developmental disabilities, consisting of the development of a Medicaid Waiver program and a Personal Support program and the expansion of the Family Support Program.

- TennCare eligibility criteria for Medicaid Waiver home and community based services should include persons who have developmental disabilities.
- Applicants for services who do not have cognitive disabilities should not be required to undergo intelligence testing in order for eligibility to be determined.



- Responsibility for administering services for persons with developmental disabilities should be assigned to the Division of Mental Retardation Services (they have experience in administering Waiver programs).

- Information and referral and access to the system should be easy, flexible, competent, consistent, and timely.
- Persons with developmental disabilities should be provided the opportunity and support to self-direct their services.
- An adequate provider network for developmental disabilities services should be developed.
- Strategies to expand the supply of

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*Persons with developmental disabilities should be provided the opportunity and support to self-direct their services.*

skilled direct support professionals should be developed and implemented.

- The Division of Mental Retardation Services' quality management system should be reviewed and expanded as needed to ensure it is responsive to services developed for persons with developmental disabilities.
- The Division of Mental Retardation Services should establish an ongoing planning process to guide the development and evaluation of home and community-based services for people with developmental disabilities.

The report has been delivered to the Governor, all legislators, and Tennessee Department heads. Although the recommendations received early support from the Division of Mental Retardation Services, that support vanished when the funding to provide the recommended services was not included in the Governor's FY 2009 budget for the Division. Fearful that the recommendations would not be implemented, some of the original members of the Task

Force have continued to work together to educate persons with developmental disabilities, family members, and the general population about the challenges persons with developmental disabilities face when they seek home and community-based services. Persons with developmental disabilities and their families are now educating their legislators about their needs and the recommendations made by the Task Force in hopes that funding will be appropriated for needed supports and services even though such funding is not requested in the Governor's 2009 budget.

Initial funding would provide services for an estimated 900 persons with developmental disabilities. This is a relatively small number of persons served compared to the estimated 12,078 to 39,252 persons with developmental disabilities in Tennessee. However, it is significant in that it would be a reasoned approach to begin to meet the needs of the developmental disabilities community. This is Tennessee's initial step in fulfilling the promise!

[www.DLACTN.org](http://www.DLACTN.org)



## ADD Still Needs Your Pictures

ADD is pleased to have received many pictures from grantees in response to our photo request. We are currently using these images in our newsletter and on posters, folders, brochures, websites, and a variety of other materials. We are always looking for new images. Sending ADD a picture is a great way to shine a national spotlight on your programs.

For more information, including picture specifications and waiver forms, please contact Rebekah Yeager at [Rebekah.Yeager@acf.hhs.gov](mailto:Rebekah.Yeager@acf.hhs.gov).

## Illinois Council's Direct Support Professional Initiative



Direct Support Professionals (DSPs) play a critical role in the lives of people with developmental disabilities and their families. DSPs support people with disabilities in activities of daily living, social activities, personal

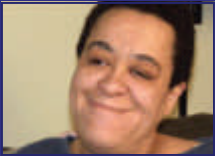
contacts, coordination of health care, community interactions, and more. The quality of support people with disabilities receive from DSPs has a profound influence on their daily lives. In Illinois, as in the rest of the nation, the community support system faces high direct support turnover and vacancy rates. Inadequate wages and benefits, lack of career and educational ladders, and societal devaluation of helping professions take their toll on this vital workforce endangering those who rely on this support.

The Illinois DSP Workforce Initiative, with support from the *Illinois Council on Developmental Disabilities*, brings together stakeholders to address the scarcity of qualified people available to provide direct support for people with developmental disabilities living in communities throughout Illinois. This group has developed a plan for change in Illinois to improve the recruitment and retention of DSPs. The goals of this plan focus on the following:

- Improve recruitment and retention strategies in Illinois
- Increase the wages and benefits of DSPs and supervisors
- Create and disseminate tools that employers can use to recruit and retain quality DSPs
- Improve educational opportunities for DSPs and supervisors

- Create career ladders for DSPs to advance professionally
- Improve the public image of DSPs and the value of their work
- Develop a professional association for DSPs in Illinois with national affiliations
- Improve mentoring and supervision practices in Illinois
- Identify methods for tracking workforce data and using this data to evaluate and report on workforce conditions

Through this initiative, an exciting resource has been developed-- *Find, Choose, and Keep Great DSPs: A Toolkit for people with disabilities and families*. This toolkit is designed to provide easy-to-use tips and strategies to help people with disabilities and families find, choose, and keep high quality DSPs (also called personal assistants, home care workers, personal care attendants, etc.). There are two different versions of this toolkit — one for people with disabilities and one for their family members and support providers. The Toolkits were created by the project partners: the Institute on Disability and Human Development at the University of Illinois at Chicago as well as the Institute on Community Integration at the University of Minnesota. They were developed and reviewed by people with disabilities and their family members to make sure they are appropriate, relevant and accessible for people with a wide range of disabilities. Customized training can also be provided along with the Toolkits. For more information contact Katie Keiling at [kkeiling@uic.edu](mailto:kkeiling@uic.edu) or (312) 996-1002 or visit [www.ildspinitiative.com](http://www.ildspinitiative.com)



Photos courtesy  
of the Illinois  
Council

# Wisconsin UCEDD Delivers a Sound Response



The Dane County Developmental Disability system has long prided itself in developing creative support models in promoting self-determination for individuals with disabilities. The University of Wisconsin-Waisman Center (Wisconsin's UCEDD) Community TIES program is partnering with Dane County in initiating another such effort. The program is titled "Sound Response."

various burglar alarm systems, sound detectors, floor pressure pads, personal assistance systems, and door and window sensors. The system has been proven reliable, and can operate on internal re-chargeable batteries in the event of a power failure. This type of remote support is being embraced in the field of aging adults and it is anticipated that as technologies continue to develop, the integration of those technologies and supports for people with disabilities will foster new levels of independence.

Sound Response strives to supplement direct staff support through the creative use of technical/mechanical supports

Dane County often approves and funds ongoing overnight staffing for individuals who may need occasional overnight support. This support model assures safety but is typically staff intensive, costly, and somewhat intrusive (individuals are required to share their homes with live-in staff who frequently change). An alternative approach when nighttime intervention is warranted only rarely, is to offer a combination of off-site monitoring with quick response by familiar, professional staff, as an effective support model for assuring safety and promoting independence.



This model will not include individuals who are medically or behaviorally at risk, but who typically sleep through the night and have paid overnight

staff "just in case". It does not affect the support participating individuals currently receive during awake hours. The Department of Human Services, in concert with developmental disability residential agency providers, have identified individuals who currently have overnight support, but who could benefit from this new support model.

Sound Response strives to supplement direct staff support through the creative use of technical/mechanical supports. These technical/mechanical supports are in the form of a variety of monitoring devices, which already are being utilized in private homes and security systems. These include speaker phones, pagers, motion detectors, smoke detectors,

Sound Response responders are strategically located in Dane County, which are staffed from 9:00pm to 7:00am. Staff positions are professional and require a degree in human services and extensive experience in the field of developmental disabilities. In addition, staff receive standard training (Blood Borne Pathogens, Universal Precautions,

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First Aid, CPR, Medication Administration, Crisis Response, etc.) and also receive specific training around the individuals that they support. Sound Response staff are required to spend a designated amount of time with each person every month.

Obtaining Sound Response support is facilitated through a referral process. Once a referral is received and the respective person's team feels the referral is appropriate, Sound Response staff meet with the person and their team to assess the supports necessary to offer a more least restrictive living environment. Sound Response, through the assessment and intake process, receive relevant records and will develop individual protocols to be used at the monitoring site. Sound Response becomes a part of the person's life.

The system combines a number of these devices (based on the individual's needs and wishes), allowing off-site response staff to be alerted and to provide support and intervention only when necessary. Individuals are trained on how to activate each device if they need assistance. Every participating residence has at least one monitoring device placed in the most appropriate area. Sound Response staff and the person's team, determine the amount of equipment necessary to support the person. The equipment is portable and can be moved and or modified to accommodate changing levels of support.

Residential support staff activate the system at the end of their shift, which notifies the off site monitoring staff that the system has been activated. Residential staff are required to call before leaving participant's homes. They report illnesses, behavioral concerns, unusual events, or if a participant is going to be arriving home at a later time. This allows Sound Response staff to change individual protocols on a nightly basis if necessary. It also permits monitors to call back, converse and have more intimate contact with the participants supported that are still awake.

All alarms are received by a computer through the phone line, which is monitored by the two Sound Response staff at the monitoring site. The computer displays the exact sensor activated, client notes, protocols, medications, contact numbers, and other necessary information. Depending on the type of the unexpected activity (this could include sounds, activity, smoke, or commotion), the Sound Response staff establish two-way contact with the person

over the phone (or speaker phone) to ascertain immediacy of need; drives to the residence to provide necessary support; contacts the current crisis support team; involves the necessary authorities (Fire, Police, EMS); or uses any combination of these responses. Responder locations are strategically placed to encompass all households to be reached within 5 minutes.

Sound Response began supporting three homes in July 2002. As of July 2007, approximately 165 individuals, comprising 110 households, are using Sound Response. Additional responding staff have been hired and trained and additional households are being assessed for types of monitoring devices. The system has expanded from one monitoring site to adding five responder sites throughout Madison, WI and southwestern Dane County.

In addition to the current system of supports, a new feature of supports has been added. It is called the Rotating Responder. The Rotating Responder, utilizing the established technology of the current Sound Response program, provides scheduled and unscheduled visits/responses to participants that require more intensive care. This additional program began in November 2005.

Participants have reported a feeling of independence because they are the only ones in the home at night. One participant states, "I can get more rest during the night because people are not in my living room making noise (watching TV etc.)". Individuals also report a sense of security knowing that a familiar voice/ face is quickly available at the touch of a button.

There is a continuing interest from other networks throughout Wisconsin and other states as well as the Dane County Aging network to utilize the Sound Response system. It is anticipated that the Sound Response system will continue to grow significantly in light of current funding cutbacks. It provides both an increase in individual choice and freedom while providing a cost efficient measure of protection and safety.

<http://www.waisman.wisc.edu/cedd/>

# Family Support 360 Programs

## District of Columbia: Family Empowerment Center Sibshop

In October 2007, The Quality Trust Family Empowerment Center (FEC) hosted its first Sibshop (Sibling Workshop). The purpose of this workshop series is to foster opportunities for brothers and sisters of children with developmental disabilities to obtain peer support and education within a recreational setting.

Brothers and sisters of siblings with disabilities are often overlooked as it relates to their unique role as a family member. They have much to offer and require equally as much peer and educational support as they may become the future caregiver of their sibling. FEC's purpose in hosting this series is to educate, empower and groom future leaders, advocates and caregivers in the District of Columbia.



“Our Sibshop meets the first Saturday of each month from 10am -2pm with an average of 15 participants. We use a wellness approach and utilize all members of our staff to help make it a success. We added a theme based curriculum to compliment the standard Sibshop curriculum. Each month we welcome a special guest around a specific theme. The guest is often an adult sibling who shares his/her profession as well as the common joys and concerns about being a brother/sister to a child with a disability. We also have teen and young adult mentors who are also siblings. The mentors bring their perspectives that help both the facilitators and participants.”

<http://dhs.dc.gov/dhs/cwp/view,a,3,q,492383,dhsNav,|30989|.asp>

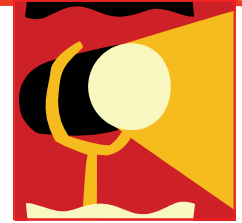
## South Dakota: PLANS Project

The state of South Dakota is one of the nation's most rural areas. Close to 60% of South Dakota's total population live in small, rural communities of 4,000 or fewer people, with communities of under 500 people comprising a large portion of this population group. Only nineteen communities have community based providers available to provide services to adults with developmental disabilities, so access to formal adult services can mean a move of 100 to 200 miles away from home. Many other services such as counseling, accessible transportation, continuing education, and specialized medical care are only available in the larger communities. The Family Support 360 PLANS Project has provided the opportunity for adults with developmental disabilities to choose to remain in their rural communities, without having to move or even travel for these much needed services.



Replicating these services statewide and hiring Coordinators to provide Family Support 360 services to families has been a long-term goal of the Project since its inception. Beginning in January 2005, the Project hired the first Coordinator to serve the southeastern portion of the state, covering an area consisting of twenty-one counties. Then in March 2005, a second Coordinator was added to provide services in an eleven county area in northeastern South Dakota. Finally in May 2005, a third Coordinator was added to serve 9 counties in western South Dakota. All of the Coordinators also serve at least one Native American reservation. Early on it became evident that the need for the services in southeastern South Dakota was more than one coordinator could handle, so a second Coordinator was hired in October 2007. Thus today, the Family Support 360 PLANS Project has implemented services in 41 of the 66 counties with the hope that before the completion of the project, services will be available statewide. [www.state.sd.us/dhs/ddc/](http://www.state.sd.us/dhs/ddc/)

# Spotlight on Self-Advocates



## High McCleary's Home Sweet Home

Hugh McCleary is feeling pretty relaxed in his new home. He's got cable TV, two telephones, central air conditioning, beautiful wood floors, washer and dryer units and several pieces of furniture—including a living room set and several chairs donated by friends—that may or may not be in the same place next week. "If I don't like where something is sitting, I can just move it around in different ways and put them where I want," says Mr. McCleary. "If people don't like it I say, 'Well by golly, it's my house. I'll move it when I get ready!'"

Which is obviously the prerogative of any homeowner. Furniture where you want it. Guests when you want them. Pictures on the wall—or not. But pictures on the wall is something Mr. McCleary has in abundance, including one of himself smiling at three years old. In addition, there are numerous pieces of framed artwork donated by folks in Memphis, through Mr. McCleary's brother and sister-in-law. "She told me next time she comes she's going to bring a carload of pictures," says Mr. McCleary. "I don't know where I'm going to put them all!"

Having more than he needs instead of not enough is a problem that Mr. McCleary hasn't always had. He has traveled a long road to get to this point in his life: living on his own, in his own home, in the new Rainwood Subdivision of Nashville. As an adult with a disability on a very limited income, Mr. McCleary has lived in large institutional settings, group homes and rental apartments.

In 2002, the Down Syndrome Society of Middle Tennessee forged a partnership with The Arc of Davidson County to address the enormous obstacles persons with disabilities face in trying to achieve homeownership, and in safe and affordable neighborhoods. Using a model initiated by Habitat for Humanity, the Home Of Your Own (HOYO) project builds houses by counting on donations and volunteer labor, then offers them for purchase to qualifying individuals with disabilities, at a 0% interest

rate, arranged by Pinnacle Financing. That interest rate allows Mr. McCleary to make a monthly mortgage payment that is actually lower than his previous monthly rental fees.

And, similar to the Habitat process, the selected HOYO candidates must complete homeownership classes and commit to 200 "sweat equity" hours of labor to the construction process. If the new homeowner cannot accomplish this himself, his family and friends can work on his behalf.

HOYO coordinates the several agencies and individuals that make the house happen, including, in Mr. McCleary's case, site supervision and skilled volunteers from Habitat for Humanity staff, The Arc of Davidson County, Ron Butler from The Arc of Tennessee, New Hope Construction, and Mid-TN Supported Living, Inc., whose staff contributed many of the sweat equity commitment hours.

For the past several years, Mr. McCleary has been assisted in his living circumstances by Mid-TN. "Hugh will start dodging us if he feels that we're getting a little too nosy, a little too pushy—and we know to listen to that. So we try to be real

sensitive to that balance of shared control, and help Hugh make informed decisions. We might not always agree with him, just like we don't always agree with each other's choices all the time," says Denine Hunt, former executive director of Mid-TN.

When funding becomes available, Ms. Hunt and her staff routinely talk to the different folks they support about their interest in having their own homes. Currently, 32% of the people Mid-TN supports are homeowners. "As an agency, we really value people being in control of their own lives," says Ms. Hunt, "and homeownership certainly supports that value. Probably more than anything else."

Mr. McCleary expressed an interest to buy his own place, and fortunately, the HOYO project was taking applications. This is not to say that his decision to join the ranks of homeowners was an easy or quick one. In reality it took a






couple of years, while Mr. McCleary was living in an apartment nearby the Mid-TN offices on Murfreesboro Road in Nashville.

“He really felt safe living in an apartment at the top of the hill,” says Jill Chapman, Mid-TN’s Support Team Leader, and Mr. McCleary’s case manager. “He liked being able to walk down to the office and pop in when he wanted, or when he needed to know what was going on. He liked this neighborhood—he knew his landlady, the maintenance workers. He had lived there since 1999. He knew all the people at H.G. Hills and the Kroger. But then things in the neighborhood started changing, and he no longer felt comfortable walking down to the bus stop or to the store.”

So far, Mr. McCleary has been pleased with his new community that has been sprouting up around him. “I’ve got some fine neighbors,” he says. “One planted some flowers in my yard before I moved in. And I thought, now she was nice!” His next door neighbor is Kathy Bledsoe—another Home of Your Own recipient—who also is supported by the staff at Mid-TN. Mr. McCleary understands that there was groundbreaking on his new home, in more ways than one. “What about other people who have disabilities?” he asks. “Do they have homes like this? I don’t think so. I don’t like group homes for our folks. Maybe they can get more homes opened up where they can live independently on their own. I’d like to see other people have things like this too.”



**Notice of proposed rulemaking (NPRM).**  
**Developmental Disabilities Program**  
DEPARTMENT OF HEALTH AND HUMAN SERVICES  
45 CFR Parts 1385, 1386, 1387, and 1388 RIN 0970-AB11  
This rule proposes clarifications and new requirements to implement the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act of 2000). Notice of proposed rulemaking (NPRM) [Issued April 10, 2008 Federal Register: April 10, 2008 (Volume 73, Number 70)]  
<http://www.acf.hhs.gov/programs/add/NPRM.html>

**DTV: The Digital TV transition:**  
**On February 17, 2009** all full-power broadcast television stations in the United States will stop broadcasting on analog airwaves and begin broadcasting only in digital. Digital broadcasting will allow stations to offer improved picture and sound quality and additional channels. **Find out more about whether or not you will be impacted by the digital TV (DTV) transition.** Go to [www.dtv.gov/whatisdtv.html](http://www.dtv.gov/whatisdtv.html).



The next ADD Update will address **Family Support**. We need stories about what you are doing to help families with a member with a disability stay together and thrive. Programs designed to assist parents or support

siblings would be good candidates.

In addition, we're interested in hearing about programs designed to help individuals with **autism or Traumatic Brain Injury**

We're also looking for **self-advocates to profile, as well as collaborative projects to highlight.**

Please send your stories to Rebekah Yeager at [Rebekah.yeager@acf.hhs.gov](mailto:Rebekah.yeager@acf.hhs.gov).

### **Administration on Developmental Disabilities**

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U.S. Department of Health and Human Services  
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### **HHS Career Fair for People with Disabilities**

The Department of Health and Human Services' Office of Diversity Management and Equal Employment Opportunity and Office of Human Resources, along with the Employee Assistance & Recruiting Network, the National Employment Team and the Council of State Administrators of Vocational Rehabilitation, hosted a **Career Fair for People with Disabilities** on May 29, 2008 from 9:00 AM until 3:00 PM, at the Hubert H. Humphrey Building Great Hall.

This event provided an opportunity for job seekers with disabilities to market their skills to HHS hiring managers and representatives from other federal and local government agencies.

Job seekers were also able to attend workshops to learn about procedures federal agencies use to hire people with disabilities (Schedule A), how to write an effective summary of Knowledge, Skills, and Abilities (KSA) when completing a federal job application, and preview some of the latest computer assistive technology available to help make the workplace more accessible to people with disabilities.

For more information: <http://www.hhs.gov/odme/>